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ABSTRACT

Parents of children with disabilities are frequently asked to tell all or part of their family's life story. These stories are potentially powerful ways to develop empathic relationships among parents and professionals. This document discusses ways parents can prepare and present their stories so that key themes are emphasized and the information shared is used as a prompt to make improvements within a program or system. Some of the key issues discussed include: (1) what's the purpose of telling your story?; (2) who is your audience?; (3) how should your story be organized?; (4) how can you find and use your voice?; (5) how to work with props or audio-visuals; (6) how to deal with personal emotions when telling your story; and (7) how to get feedback after your presentation. Resources on telling your story, public speaking, and stories that have been told are included. (SG)

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NECTAS

EARLY CHILDHOOD BULLETIN

FAMILY EXPERIENCES: WAYS TO LEAD CHANGE THROUGH TELLING YOUR STORY

By

GLENN GABBARD

SPRING

1998

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EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NECTAS

Spring 1998

FAMILY EXPERIENCES:

Ways to Lead Change Through Telling Your Story

By Glenn Gabbard

NECTAS at the Federation for Children with Special Needs, Boston, Massachusetts

I recently attended a conference about model programs serving children with disabilities and their families. After one parent gave a particularly moving account of her family's struggles, the audience took a break. During the break, I overhead a remark from another audience participant. "I don't know if I can listen to any more tear jerking stories," the person complained. "What's the point?"

I was initially startled by the remark, then insulted. How could someone be so callous as to question the experience of a parent? As a parent of two children who receive special education services, I took this comment personally — as if the person were talking about my story — and telling me that it wasn't worth listening to. As I thought more about this situation, however, I realized the problem was not one of insensitivity, but that somehow the story had no impact on some listeners. It did not move them to think and consider using the themes and information as a prompt to change their personal and professional lives.

Whether it be to pediatricians, neighbors, legislators, therapists, conference audiences, teachers, administrators, or peers, parents of children with disabilities are frequently asked to tell all or part of their family's life story.

Parents reveal their stories as a way to understand the past in relation to an imagined future for themselves and their children.

Stories help us connect. Stories also reveal the details, the impact of systems on the daily lives of families and children. They are a powerful way to develop relationships among parents and professionals. These stories are what connect us to our work and to each other in meaningful ways. They deepen our understanding of individual and shared experiences. Stories often spur change in systems that seem impossible to understand. They can also help clarify disagreements.

> ***"Stories help us connect. Stories also reveal the details, the impact of systems on the daily lives of families and children."***

Storytelling can also be a huge risk. By sharing a story, you can easily make a point; however, you can also be vulnerable to criticism or misinterpretation. Often, the powerful lessons that these stories reveal are not fully appreciated; often parents grow fatigued with revealing private experiences that are frequently painful to recall.

This edition of the *Early Childhood Bulletin* will focus on ways parents can shape their stories so that key themes are emphasized and improvements are made within a program or system. We'll cover some of the key issues to consider in preparing and presenting a story. We've also included some additional resources to consider if you wish to pursue this topic.

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Family or parent involvement has become a hallmark of many programs and services for young children with disabilities and their families. Though being "involved" may translate into many different kinds of activities and interactions, one of the ways that parents can make a difference is by telling their story.

In the next pages are outlined some important guidelines to consider when a story is to be told. The guidelines are designed around three phases of storytelling:

1. ***Preparing what you have to say***
2. ***Presenting the story***
3. ***Following up the story and assessing the impact of your story***

It's a good idea to spend at least some time on each of these phases — even if the story that you tell is one you've told before, even if the audience to which you tell it is a familiar one.

1. PREPARING THE STORY

What's the Purpose?

Parents tell their stories in many situations, sometimes when they are invited, others when they discover the opportunity informally. Parents speak in formal settings, including parent training, professional development, keynote speeches or panels for conferences, legislative hearings, school presentations to teachers and students. A group of parents gathered at a recent Part C conference in the Midwest and discussed some of the key purposes for speaking out. They mentioned the importance of using one's own experience to bring change and broaden their experience to apply to others.

- Turning grief and anger into constructive energy by talking publicly
- Helping service providers by sharing stories for effective networks to programs
- Reinforcing values to guide a family's commitment to themselves and their children
- Influencing public opinion by illustrating how policies affect families
- Helping yourself and others to feel less alone in efforts to make change
- Marketing key strengths of early intervention to legislators and other policy makers
- Entertaining others
- Sharing information that cannot be easily presented by charts or graphs with others who do not directly experience the problem
- Raising awareness and promoting sensitivity to the experience and knowledge that grows from these experiences

Where Do Family Stories Get Told?

"As part of our Parent-to-Parent program, I often meet families who have newly diagnosed children. I find that telling the story of my own children's births helps create an almost immediate bond."

– Parent Support Staff Member

"Managed care has made life for kids with special/health care needs a real nightmare in our area. I told my story to my HMO's board of directors to help them understand how unique my family and others like mine are."

— Parent Representative, State Interagency Coordinating Council (SICC)

1. PREPARING THE STORY

WHO'S THE AUDIENCE?

It is important to think a bit in advance about who will hear your story. A little ground work can help to make the story effective and help you be comfortable in telling it. Who is in the audience can help you to decide which parts to emphasize and, more importantly, why you are telling it. Aspects can change depending on the audience: a story about a wonderful preschool program can emphasize the need for funding with a group of legislators considering the next year's budget; to a group of preschool teachers, it can emphasize the importance of parent/teacher communication and collaboration.

HOW TO ORGANIZE A STORY

Although most stories have a beginning, middle and an end, they can also vary in length — some are 30 seconds long; others can last over an hour. Engaging stories rely on a beginning that "hooks" the listener who then listens for the details in the middle of the story, and awaits the punch line at the end. The ***beginning*** sets the stage, identifies the key characters and location, and gets the listener interested. The ***middle*** — where the plot thickens — adds details, examples, and interesting information to understand the key ideas and people. The ***end*** usually ties things together and often gives an idea of what can be learned from it — what was the theme or lesson? Sometimes this theme can be stated directly; at other times, it is best to let the listeners draw their own conclusions.

☑ Some questions to consider:

- ✓ Who is your audience?
- ✓ What is their purpose?
- ✓ What is their education level?
- ✓ How many people are you speaking to?
- ✓ Age?
- ✓ Where are you presenting?
- ✓ Numbers of men and women?
- ✓ Did the audience pay to hear you?
- ✓ Numbers of parents and professionals?

The Organization of a Story

Beginning

- Where does the story occur?
- Who are the important people?
- When did the story take place?

Middle

- What happened first, second, third, etc.?
- What was the major conflict?
- What were some of the key feelings elicited?

End

- What happened to conclude the story?
- How was the problem resolved?
- What was the key theme you learned?
- What is the key theme you want the audience to understand?

2. PRESENTING THE STORY

Finding and Using Your Voice

The way a story is told is often as important as the story itself. To be an effective storyteller you must have something to tell, someone to tell it to and the ability to make yourself heard. Some suggestions on presenting:

☑ RELAX

Before you begin to speak, take a few deep breaths and slowly scan the audience for familiar faces.

☑ PROJECT

With large audiences, use a microphone. In smaller groups, project your voice with confidence.

☑ PACE

The most frequent problem with nerves is they make us speed up our presentations. Remember to speak calmly and slowly — just a bit slower than normal conversational style. Good listeners require some processing time.

☑ EYE CONTACT

It's always helpful to establish clear and frequent eye contact with your audience. Even in small groups, you will find listeners who appear to be attentive; some folks may nod or smile.

It's often useful to consistently look at familiar or sympathetic faces in different parts of the audience. Look around frequently at these groups so that all of the audience feels included.

☑ HUMOR

If appropriate, it may be helpful to use a bit of humor. Test any humorous comments with friends or colleagues to see if it works for them. Avoid making any one group (professional or parent) the butt of humorous comments. Teasing and sarcasm are not a good idea — one person's idea of a sarcastic remark might be another's insult.

☑ GIVE THE AUDIENCE TIME TO ASK QUESTIONS

- Allow time the end of your presentation for audience members to ask questions.
- If someone asks a personal question that hits a raw nerve simply say, "I find that question difficult for me and I would really rather not answer it."
- Be comfortable saying, "I don't know, but I can find out for you" if you can't answer a question immediately.

Where Do Family Stories Get Told?

"You know, as a preschool director, the connection and empathy I feel with others — parents and professionals alike — is so powerful when I hear stories that connect somehow with my own. I get tired sometimes of hearing broad statements about how important collaboration is in thinking about family centered services and programs. What really makes a difference for me is when I hear stories about what happened today at the center...what kind of difference we made in the lives of the families we serve."

– Community Preschool Director

2. PRESENTING THE STORY

☑ WORKING WITH PROPS, OR AUDIO-VISUALS

- The use of AV materials such as overhead transparencies, slides, videotape selections photographs, and computer-enhanced presentations can be helpful tools.
- Know how to work equipment yourself. You cannot depend on someone being there who knows what you need.
- Be sure the equipment is working.
- Be sure that your aids are an enhancement of what you are saying and not a distraction.

☑ WHAT IF I CRY?

For even the most experienced speakers, telling a story that reveals a personal or emotional time can be difficult. Crying is, of course, perfectly acceptable; however, you need to be aware of the audience and their need to understand your emotions and your message. Also, the last audience response you want from telling your story is pity or confusion. Some tips from parent storytellers:

- If you start to cry, pause long enough to take three or four deep breaths, and then go on. The audience will appreciate your taking the time and being able to hear the rest of your presentation.
- Sometimes it is useful to explain to the audience that you need to collect yourself and that you really want them as much to understand your what you have to tell them as well as how emotionally difficult it is for you.
- Mentally focus on something that makes you laugh inside; this sometimes evens out the fear and sadness enough to let you go on.
- Take a small squeezable rubber toy or some other object that will fit in the palm of your hand. If you start to cry, squeeze the toy to relieve some of the tension.
- Avoid someone "rescuing" you by interrupting and interpreting what you mean. If you still have a message to convey, take the time to collect yourself and then go on.

Where Do Family Stories Get Told?

"There is so much misinformation in our state about inclusion and natural environments. Recently, I testified at our local school committee meeting and told them how my son was part of his local little league team, even though he uses a wheelchair. A few of the committee people came up later to thank me for showing them some real examples of what we mean by including *everyone*."

– Parent Advocate

"For the first time in our state, we have to request additional funds for our Part C programs from our legislators. We've set up training in marketing and public awareness for parents and professionals whom we are asking to visit legislators and tell their stories."

– Part C Coordinator

3. FOLLOWING UP

HOW CAN I GET FEEDBACK?

Understanding how listeners heard your story is as important as preparing and telling it. If possible, ask trusted colleagues or friends to listen to your presentation and to let you know what they thought of it. Prepare focused questions and listen carefully to their responses. This will help you develop the story and emphasize effective features.

Some questions to ask when getting feedback:

- What key phrases and words caught your ear?
- What was the most successful part of the presentation?
- What was most difficult to understand?
- If you knew the story was going to be told again, in what ways could it be different?
- What were the major themes?
- How did the audience respond?
- What about volume? Pace?
- Did I use humor effectively?
- Did the story make logical sense?

If there is an evaluation form for the activity in which you were speaking, ask to review the results. If you are speaking in an informal setting, ask someone to observe how the audience responds. This can be useful in meetings, training sessions, or even small groups in which stories are told. In some school or hospital settings, families ask a friend to act as an informal "critic"; this individual can give you feedback about the interaction if it seems appropriate.

☑ A Final Note to Consider

As children grow older and more independent, it's important to consult them about the story details and, sometimes, whether or not the story should be told at all. It's important to remember that as children mature, some will be asked to tell their stories and should understand the importance as well as their right to keep details that they deem private to themselves.

Where Do Family Stories Get Told?

"When I need to make any big changes in my child's Individualized Education Program (IEP), I know that there may be some resistance. I usually introduce the need for a change with a story about my child that illustrates how the change could really help. It helps the group to become more child centered rather than focusing on possible conflict between me and them."

– Parent Representative, Local Interagency Coordinating Council (LICC)

RESOURCES

ON TELLING YOUR STORIES

University of Wisconsin-Madison, Waisman Center, Early Intervention Program Parent Projects (Producer), & Geier, D. and Thompson, C. (Directors). (1994). Telling your family story...Parents as presenters [Videorecording]. Madison, WI: University of Wisconsin-Madison, Waisman Center. 1 Video Cassette plus accompanying video guide. 28 min.

"Telling Your Family Story...Parents as Presenters." Video Cassette. Waisman Center, Early Intervention Parent Projects, University of Wisconsin, Madison. (1994). 28 minutes. Waisman Center.

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"Using Stories as Catalysts for Change." *Parent Leadership Program Training Manual* (March 1996). Lansing MI: Michigan Department of Education. 608 West Allegan Street, Lansing MI 48933 517.373.6335. A useful set of activities designed to foster skill and knowledge building for parent leaders involved in policy making capacities.

ON PUBLIC SPEAKING

Hoff, Ron and Barrie Maguire (1992). I Can See You Naked. New York: Andrews & McMeel.

STORIES THAT HAVE BEEN TOLD

Simons, Robin (1987). *After the Tears: Parents Talk About Raising a Child With a Disability.* New York: Harcourt Brace. A collection of interviews and stories from parents who share their experience of becoming parents.

Featherstone, Helen (1981). *A Difference in the Family: Living With a Disabled Child.* New York: Viking Press. A classic account of one mother's experiences as a parent and advocate.

Coles, Robert (1990). *The Call of Stories: Teaching and the Moral Imagination.* New York: Houghton Mifflin. The nationally renowned psychiatrist and humanist reflects on the importance of learning from the stories we tell and hear.

Mairs, Nancy (1998). *Waist-High in the World: A Life Among the Nondisabled.* New York: Beacon Press. A recent collection of eloquent essays reflecting on the experience of disability and change.

THANK YOU

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An Important Electronic Resource for Parents Serving on ICCs

NECTAS is pleased to sponsor the ICC Parent Leadership listserv.

Parents serving on ICCs play a unique role. They are often perceived as representatives of large groups of parents within communities and their own personal experiences are considered, many times, to be representative of others. The purpose of this listserv is to facilitate networking and discussions related to the unique leadership challenges and opportunities, etc.

The ICC Parent Leadership listserv is a closed list, which means the request to subscribe are made to a list moderator. Glenn Gabbard, NECTAS Technical Assistance Specialist at the Federation for Children with Special Needs in Boston, MA will moderate. Email Glenn with your subscription request at: "ggabbard@fcsn.org"

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